

Frequently Asked Questions: Autism and Children and Young People

These frequently asked questions are about autism. Autism is a developmental disorder and affects how we see, hear and feel the world around us. This can be confusing for some people. Autism is a condition that people are born with but which doesn't always get diagnosed straight away. Each and every one of us is different, which makes us all individuals.

About some of the terms used in these frequently asked questions:

- These frequently asked questions use ASD (short for 'Autism Spectrum Disorder') to refer to any form of autism.
- The term 'SEND' is a short version of 'Special Educational Needs and Disabilities'.
- The 'Open Minds Partnership' or 'OMP' is the name children and young people decided upon for the partnership between the providers and commissioners of children and young people's emotional health and wellbeing, and mental health services in Calderdale. This is the new name for what was known as Calderdale Children and Adolescent Mental Health Service (CAMHS). The OMP includes: the two providers, Northpoint Wellbeing and South West Yorkshire Partnership Foundation Trust, and the two commissioners: Calderdale Clinical Commissioning Group and Calderdale Council.
- The First Point of Contact (FPoC) is the central point where all Children and Adolescent Mental Health Service (CAMHS) referrals are received. The service provides consultation, support, advice and referral guidance to professionals in the Calderdale locality who have questions or concerns around the mental health/emotional wellbeing of children and young people.
- 'Children and young people' referred to in these Frequently Asked Questions are those aged 5-18 years old.

1. How does my child or young person get an assessment for ASD?

You (if you are a parent carer), your child's GP, or another professional who knows them, will talk to your child/young person, and you, about making 'a referral' to the First Point of Contact (FPoC) for the Open Mind Partnership (OMP). The OMP oversee ASD screening.

You, or the person referring your child/young person to the FPoC, will need to provide information to them about your child/young person, and any difficulties

they may have. Questions two and three explain more about how screening and the assessment process works.

2. How long does it take for my child or young person to be screened for ASD after a referral has been made?

Once an initial referral has been sent to the First Point of Contact (FPoC), it goes through a 'screening process'. A specialist FPoC worker reads the information provided on the referral form and phones parent carers and schools to collect more information and explain what's going to happen next.

If there is enough information to move ahead, the FPoC sends a 'neuro-developmental screening questionnaire' to parent carers. Unique Ways (the local charity that provides support for parents/carers) can help parent carers fill this in. Their web site is: www.uniqueways.org.uk/.

The child or young person's school is also sent a questionnaire.

Parent carers and schools are asked to complete and return their questionnaires within four weeks. This can take longer during school holidays or where the FPoC needs more information.

A reminder is sent part-way through, after two weeks to give help, if parent carers and schools say they would like this.

Once the questionnaires are returned, the information is gathered together by the FPoC and read by a clinical psychologist from the South West Yorkshire Partnership Foundation Trust (SWPYFT).

After they've read the neuro-developmental questionnaires the assessment team sometimes feel it is helpful for a member of the team to meet with your child or young person, to get more information. This is known as a 'Choice' assessment and is usually carried out by the 'pre-diagnosis therapeutic practitioner'.

This face-to-face meeting can help to decide whether your child or young person's case should be placed on a waiting list for an ASD assessment or whether it would be better for your child/young person and parents/carers to get help from other organisations.

If your child or young person's case is not added to the waiting list for an ASD assessment, the FPoC will write to you to let you know why they have not been offered an assessment. The FPoC will suggest alternative services which might be helpful.

A letter is also sent to your child/young person's school, their GP and the person who referred them to the FPoC. This also makes suggestions of where to get further help.

3. How will my child or young person be assessed for ASD?

After the initial screening process, if your child or young person is placed on the waiting list for an ASD assessment, parent carers receive a letter from SWYPFT to tell you this has happened.

A 'pre-diagnosis information pack' is sent with this letter. This includes:

- A diagram that describes the different stages of the ASD assessment, so you know what to expect;
- A leaflet about the process for your child or young person;
- Information about help for your child or young person and you, while you wait.

All the information has been created with help from young people and parent carer groups.

4. What is the current waiting time for assessments?

The waiting time for assessments changes regularly because there is a 'waiting list initiative' currently in place.

Before this initiative was in place, some children and young people could wait up to two years for an assessment. Some waited up to 3 years.

However, because extra funding has been provided by Calderdale Council and Calderdale Clinical Commissioning Group, all the partner organisations made a commitment that children and young people would be seen for assessment within 12 months.

It is the plan to continue to reduce the waiting times throughout 2020.

5. What support is available while my child or young person is waiting for an assessment?

Northpoint Wellbeing, one of the partners in the Open Minds Partnership, provides time-limited support to parent carers of school-aged children who are on the waiting list for an ASD assessment. This support is provided by a qualified and experienced therapeutic practitioner.

Lots of families have found this service helps them to feel listened to, and to feel more confident about how they can support their child.

The practitioner can provide practical advice and strategies to help parent carers to manage the difficulties they are experiencing. They can provide information about helpful resources and websites. They can also tell you about local groups, training courses, and services that can help.

Parent carers or someone who knows your child or young person, such as their GP or teacher, can ask for this support by either:

- Visiting this web site: <https://calderdalecamhs.org.uk/asd-support/>;
- Or by calling the FPoC on 01422 300 001.

Everyone will be offered a chance to chat over the phone, with the option of face-to-face meetings if needed.

Information on the Calderdale 'Local Offer' web site has fact sheets, details of local organisations and other resources about ASD and social communication needs. The Local Offer web site for ASD is

<https://www.calderdale.gov.uk/v2/residents/education-and-learning/local-offer/send/social-communication-needs>

6. I'm thinking of having my child or young person assessed privately, not by the NHS. Will the assessment report be accepted?

It's your choice as the child or young person and parent carers, whether you wish to have an assessment carried out privately, or through the NHS/Open Minds Partnership.

Please be aware that within the Open Minds Partnership, depending on the results pre-diagnosis or full assessment stages, appropriate support can be offered to children/young people and their families regardless of whether there is an ASD diagnosis or not.

Other services (such as some special schools) may require a formal diagnosis.

If you do wish to submit a privately obtained assessment to the FPoC, these would be reviewed on a case by case basis.

The team at the FPoC would expect to see a robust assessment carried out by an appropriately qualified professional. It would need to be a 'multi-disciplinary

assessment', based on information gathered across areas such as education, health and social situations. It would also need to meet NICE (The National Institute for Health and Care Excellence) guidelines.

If your child or young person has been given a private diagnosis and the assessment meets these criteria, the Open Minds Partnership would not repeat the assessment.

The team in the FPoC can discuss this with you. They can be contacted on 01422 300 001.

7. What happens after my child or young person has been assessed?

It depends on the results of the assessment.

When the assessment is finished, you will be invited to a feedback appointment with a lead clinician to discuss whether or not your child/young person has been given a diagnosis of ASD. You will also be provided with a written report and recommendations about support that may be helpful.

Although the Open Minds Partnership does not provide post-diagnostic support, you will be provided with information about local services that can offer this support.

Children and young people who attend mainstream schools or settings are referred to the Local Authority ASD Team by the educational provider, with parental consent, following a diagnosis for Autism.

The ASD Team provide targeted support and intervention with an educational focus; training is offered to schools and settings and parents following diagnosis.

The ASD Team is part of the Specialist Inclusion Teams and includes Specialist Teachers, Outreach Workers and Speech and Language Therapists.

If the assessment shows your child or young person is **not** diagnosed with ASD, support is still available to your child/young person, and you:

- The assessment team will aim to understand your child's difficulties and discuss these with you, and will then provide recommendations about appropriate support for you and your child. This may involve help from members of the assessment team, from the Open Minds Partnership, support through school, or other organisations or groups, which would be better placed to meet their needs.

- All nurseries and schools give extra help to children and young people with Special Educational Needs and Disability (SEND) of all kinds, including ASD.
- In some cases it may be helpful to have a further assessment to help your child get the right help, such as an Attention Deficit Hyperactivity Disorder (ADHD) assessment, cognitive assessment or educational psychology assessment.

8. My child or young person is struggling with anxiety and low mood. Is there anything we can do?

Depending on the nature of the difficulty, help is available from services like: school, School Nurse, Children's Centre or Family Support Worker.

Online self-help resources can be very good at helping young people manage their anxiety and feelings of low mood.

They can also help to guide parent carers to provide the right help and support. Some parent carers have told us that they have found it useful to work through some of the following resources with their child or young person:

www.openmindscalderdale.org.uk

www.moodjuice.scot.nhs.uk/

www.cci.health.wa.gov.au/

www.nhs.uk/apps-library/category/mental-health/

<https://reading-well.org.uk/>

<https://overcoming.co.uk/7/Home>

<https://active.calderdale.gov.uk/>

<https://www.nhs.uk/live-well/>

Young people aged 11 years and older can also get live online help up to 10pm every day (including weekends) from a service called Kooth (www.kooth.com).

It might also be that organisations in the Open Minds Partnership or another organisation in Calderdale can provide some support to your child to help them manage difficulties such as anxiety.

You will be given information about this by the staff who are working with you and your child/young person.

9. I am struggling with my child's behaviours at home but school don't experience the same issues

Some young people mask their issues and difficulties at school, in an attempt to fit in and appear as though they are coping. This can lead to a build-up of tension, resulting in challenging behaviour at home. It may be helpful to speak to a Family Support Worker who can help you to think about practical strategies and routines.

Your local children's centre may be able to put you in contact with a Family Support Worker.

- More information about Children's Centres in Calderdale can be found at <https://www.calderdale.gov.uk/v2/residents/education-and-learning/childcare/childrens-centres>;
- Or you can call the FPoC on 01422 300 001.

There is also a leaflet about this in your pack.

10. Where can I get more information about ASD and support available in Calderdale?

For more information, visit:

National Autistic Society <https://www.autism.org.uk/>

National Autistic Society – Calderdale branch

<http://www.nascalderdale.webeden.co.uk/>

Calderdale Local Offer <https://www.calderdale.gov.uk/v2/residents/education-and-learning/local-offer/send/social-communication-needs>

Unique Ways <https://www.uniqueways.org.uk/>

N.B: The above information is reflective of current practice at the time of production. A review of these questions will be undertaken in 6 months' time (the end of July 2020); therefore some of the information may have changed.